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ABSTRACT

This paper discusses issues included with obtaining educational information on sexuality pertinent to the needs of people with disabilities. First, the importance of providing correct information about sexuality to individuals with disabilities for their mental and physical health is stressed. Specific areas briefly discussed are health-related issues (both general and disability-specific), appropriate and inappropriate sexual behavior, reproduction and pregnancy, and sexuality rights. Suggestions for libraries that serve people with disabilities are also offered, including suggested acquisitions and ways to provide accurate and accessible information. A list of resources includes 11 organizational resources and 18 print materials. (Contains 25 references.) (DB)



SEXUALITY AND PEOPLE WITH DISABILITIES

by Marilyn M. Irwin

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In general society, sex has been considered a taboo topic -- unless, of course, you are a radio disc jockey or comedy club comedian. Accurate information about all aspects of sexuality is often felt to be something one should keep under the counter or wrapped in brown paper, and any questions about it, if asked at all, are whispered. Overall, the topic of sexuality makes people uncomfortable, and moral and religious considerations often overshadow the need to provide accessible accurate information. Add disabilities to the equation and further complications present themselves. Sexuality information for people with disabilities and their families is available, but finding it may be a problem for the very people who need it. This article will discuss the importance of having sexuality information available for people with disabilities and raise issues for consideration by libraries.

Importance

People generally find out about sex from their parents, sex education programs in school, and from their friends -- not necessarily in that order. The accuracy and depth of information shared depends heavily on the knowledge, experience, and comfort level of the provider. It should be no different for people with disabilities. However, much of the available print material is generic in nature, rarely mentioning considerations that may be needed for a person who is disabled, and few parents and friends have the experience or knowledge to shed further light on the subject.

Unfortunately, myths about people with disabilities and sex abound. One view is that people with disabilities are either not interested in sex or are not capable. At the other end of the spectrum, people with disabilities are sometimes viewed as being overly interested in sex and out of control in their sexual behavior. Accurate information, free of stereotypical perceptions, must be available to each person who is disabled so he/she can develop a healthy view of who he/she is as a sexual being. This is true for people with acquired, as well as lifelong disabilities. Regaining a sense of sexual identity for a person who becomes disabled as an adult may be a critical component of rehabilitation.

The issue of protection is also a critical component of sexuality information for people with disabilities. Because people who are disabled are often vulnerable to sexual abuse, prevention information should be readily accessible. Allowing myth to take over reason could also mean unnecessary exposure to sexually transmitted diseases, including the fatal consequences of contracting acquired immunodeficiency syndrome (AIDS). For people with cognitive or learning disabilities, for example, the Child Development and Rehabilitation Center in Portland, Oregon, has developed an illustrated flier on

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H. J. Schroeder

condom use with limited text.

Access to accurate sexuality materials is, therefore, very important for people with disabilities, their families, teachers, physicians, and others who may provide information. There is too much at stake to depend on misinformation in this area.

Areas for Consideration

In addition to providing information to assist in the development of individual sexuality and to prevent disease and abuse, there are other basic sexuality areas for consideration. These include health-related issues, appropriate sexual behavior, reproduction and pregnancy, and sexuality rights.

Health-related issues. Throughout life, there are information needs in a number of health-related areas. For most people, gender identification is learned during the early years and is generally followed by an understanding of anticipated changes in the body (e.g., hair growth, breast development in females). While generic sex education materials may be appropriate for most people with disabilities, adaptations may be needed for others. The individual with cognitive impairments may need materials that are presented with photographs and controlled vocabulary. Brekke (1988), *Sexuality Education for Persons with Severe Developmental Disabilities*, for example, is a comprehensive, seven-part slide set covering parts of the male and female body, appropriate social behavior, menstruation, and male and female medical examination procedures. Because so much learning and questioning in this area is related to what is seen, individuals with visual impairments may need materials that consider visual limitations.

Beyond learning about body parts, people with disabilities may have information needs related to sexual functioning. Some individuals may be impacted by mobility limitations or be easily fatigued. Materials, such as Haseltine, Cole, and Gray (Eds.). (1993). *Reproductive Issues for Persons with Physical Disabilities*, may be needed to respond to requests that are disability specific. Items that discuss sexuality from the perspective of a specific disability may also discuss other health areas. Haseltine et al., for example, state that some disabilities may mask the timely diagnosis of sexually transmitted diseases, making it particularly important to include this area of instruction (p. 12).

Appropriate sexual behavior. With today's social standards, it is often difficult to know what is appropriate sexual behavior. Because the line between acceptable and unacceptable is very fine, it is equally difficult to determine how and what to teach in this area. Giving hugs as a young child is cute, for example, but it may not be appropriate behavior for an adolescent. Information seekers and providers need to be aware that this is a particular area of sexuality where moral and religious convictions may bias the types of information that are shared.

Laws clarify the appropriateness of some behaviors. Privacy, such as not touching or exposing private parts in public and respecting other people's privacy, is an area with some clear guidelines. Unwanted sexual advances toward other people, including knowledge of who should and shouldn't touch private areas, is another area with legal implications. Having clear instruction and information in these areas, particularly for people with cognitive impairments, may later eliminate legal problems and abuse.

While providing sexuality instruction and information about anatomy changes and appropriate behavior may be seen as difficult but necessary to discuss, dealing with sexual activity is probably the most touchy area to cover. However misinformed, some people consider a person with a disability to be an asexual individual, or they may think that, due to the disability, a person who is disabled should not engage in sexual activities. In any event, talking about the mechanics of sexual activity is not something that people are comfortable doing, yet the "how-to" information may be exactly what is needed. In addition to the importance of having clear information available related to safe sexual practices for people with cognitive impairments, people with physical disabilities may need instruction about sexual positions to adapt for muscular weaknesses or other limitations in mobility. Dalrymple, Gray, and Ruble (1991), for example, also discuss masturbation as "a way to relieve sexual pressure and tension" for people with autism (p. 12), including information about establishing an acceptable routine in an appropriate place. To maximize opportunities for choice by the person with a disability, and his or her

partner if appropriate, any information provided in this area should be as free of personal judgment as possible.

When people with disabilities, particularly severe disabilities, engage in activities that are not appropriate, care providers utilize various techniques to change that behavior. Several materials are available that discuss behavior management techniques for handling various types of inappropriate activities. Others, such as Griffiths, Quinsey, and Hingsburger (1989), address the specific issue of inappropriate sexual behavior.

Reproduction and pregnancy. Women with disabilities are, first and foremost, women, and many decide that they want to have children. Many men also decide that they would like to father children. Although there are often more complications when the female has a disability, the decision is generally not made easily by either individual and disability-specific considerations are often present. If the disability is hereditary in nature, for example, genetic counseling may be a factor for the male and female.

For most women contemplating pregnancy, issues for consideration include getting appropriate medical care, the possible impact of pregnancy on the body, concerns for labor and delivery, and care for the child following birth. Although a physical disability, for example, does not alter the ability for most women to be successful in all of the areas listed above, the disability does provide added cause for concern for the expectant mother. Much of that success depends on the information the women receive to assist them through pregnancy and the postpartum period. Rogers and Matsumura (1991), for example, provide an excellent guide for women with disabilities, answering questions throughout each phase.

Sexuality rights. People with disabilities deserve acceptance of their sexuality. That acceptance would not only be within the community of people who do not have disabilities, but also validation within each individual who does. A disability does not alter the right of an individual to express his or her sexuality. This includes the right to marry, parent, and care for children; to make choices about these areas; and to have access to accurate information which will enable them to make good choices and take appropriate actions.

Library Issues

Access to current, accurate sexuality information for people who are disabled and their families is available, but not often generally apparent to people outside the disability field. As increasing numbers of people with disabilities are educated in mainstreamed public school programs and continue to live in inclusive communities, generic sexuality instructors (e.g., health teachers, family practitioners, parents) will have greater needs for access to information to respond to requests. Although libraries may not have the clientele, space, and funds to justify acquisition of materials to meet the range of possible information requests, some items should be housed and networks developed to borrow others, when needed.

One source that may be of particular usefulness is Sobsey, Gray, Wells, Pyper, and Reimer-Heck (1991). *Disability, Sexuality, and Abuse: An Annotated Bibliography*. This comprehensive volume pulls together works dealing specifically with sexual abuse of people who are disabled.

As stated earlier, sexuality is a difficult topic for most people to discuss, and librarians are no exception. Due to discomfort about this topic, censorship of sexuality materials, whether deliberate or not, often impacts library collections. To provide needed sexuality information for people with disabilities, librarians must learn to face their own comfort level about sexuality **and** about people who are disabled, then move beyond that to be nonjudgmental in information sharing. In addition to stimulating healthy attitudes about his or her individual sexuality, information that is accurate and accessible could save the life of a person who is disabled.



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WHAT'S AVAILABLE AND WHERE YOU CAN FIND IT

Alliance of Genetic Support Groups

35 Wisconsin Circle, Suite 440
Chevy Chase, MD 20815-7015
1-800-336-GENE (1-800-336-4363)
fax: 301-654-7071
e-mail: alliance@capaccess.org
Web Site: medhelp.org/www/agsg.htm

This organization serves as a referral agency connecting people with genetic disorders and their families with the appropriate support groups. The organization does not offer any direct counseling. Referral services are free of charge.

The Arc of the United States

500 East Border Street Suite 300
Arlington, TX 76010
817-261-6003
fax: 817-277-3491
TT: 817-277-0553
e-mail: thearc@metronet.com
Web Site: TheArc.org/welcome.html

The Arc is a national organization on mental retardation with state and local chapters throughout the United States. Several sexuality-related publications are available from The Arc including *The Sexuality Policy and Procedure Manual* (\$3.50 each; sliding scale of \$2.50 each for 10 to 29 copies, \$1.50 each for more than 29 copies).

Centers for Disease Control

National AIDS Clearinghouse
P.O. Box 6003
Rockville, MD 20849-6003
1-800-458-5231
TT: 1-800-243-7012
e-mail: aidsinfo@cdcnac.aspensys.com
Web Site: www.cdcnac.org

The National AIDS Clearinghouse provides resources and information regarding AIDS and HIV. The database includes over 135 documents specifically designed for people with disabilities including, but not limited to, hearing and visual impairments, developmental delays, mental illness, and mental retardation. Geared towards professionals, the materials include tapes, video recordings, brochures, pamphlets, posters, and AV materials. The Center provides a catalog of these materials and charges only for shipping and handling.

National Center for Youth with Disabilities

University of Minnesota
Box 721 - UMHC, 420 Delaware St. S.E.
Minneapolis, MN 55455
612-626-2825
e-mail: ncyd@gold.tc.umn.edu
Web Site: www.peds.umn.edu/centers/ncyd

This organization offers several pieces of information regarding youth with disabilities. One title, *Issues in Sexuality for Adolescents with Chronic Illnesses and Disabilities*, is an annotated bibliography of various resources on the topic of sexuality of people with disabilities. The Center provides a free listing of the publications which they sell, including a price list and ordering information. Most publications range in prices from \$4.00 to \$6.50.

National Clearinghouse on Women and Girls with Disabilities

c/o Educational Equity Concepts Inc.
114 East 32nd Street, Suite 701
New York, NY 10016
212-725-1803
fax: 212-725-0947
e-mail: 75507.1306@compuserve

This clearinghouse provides a catalog of their many manuals, teen supplements, videos, and directories, many of which deal with sexuality issues faced by women and girls with disabilities. Most items have a charge.

National Down Syndrome Society

666 Broadway, Suite 810
New York, NY 10012-2317
1-800-221-4602
Web Site: www.ndss.org

The National Down Syndrome Society provides an information packet and list of books regarding several issues facing people with Down syndrome including sexuality issues. Packets are free of charge and include an order form for the videos, books, manuals, brochures, and booklets which the Society sells.

National Information Center for Children and Youth with Disabilities (NICHCY)

PO Box 1492
Washington, DC 20013-1492
1-800-695-0285 (Voice/TT)

fax: 202-884-8441
e-mail: nichcy@aed.org
Web Site: www.aed.org/nichcy

NICHCY is a national information clearinghouse with children and youth (birth to age 22) with disabilities as the special focus. *Sexuality Education for Children and Youth with Disabilities* (1992) was published for parents and professionals as part of their *News Digest* series. This publication deals with education related to the social-sexual development of youth with disabilities.

National Rehabilitation Information Center (NARIC)

8455 Colesville Road Suite 935
Silver Spring, MD 20910-3319
1-800-34N-ARIC (1-800-346-2742)
fax: 301-587-1967
TT: 301-495-5626
e-mail: naric@capaccess.org
Web Site: www.naric.com/naric

Serving as a national disability and rehabilitation information center, this organization maintains REHABDATA, a bibliographic database of rehabilitation, disability, and assistive technology literature. Searchable through NARIC's Web site, the database includes numerous sexuality-related entries. Some photocopies of articles are also available to individuals on a cost recovery basis.

PACER Center

4826 Chicago Avenue South
Minneapolis, MN 55417-1098
612-827-2966 (Voice/TT)
fax: 612-827-3065
e-mail: webster@pacer.org
Web Site: www.pacer.org

This Minnesota-based parent-to-parent organization has published numerous items of interest to families of children with disabilities. One of the most recent, *I'm a Beautiful Person: A Video for Parents and Youth with Disabilities*, includes teens and young adults with disabilities discussing sexuality. The video can be purchased for \$35.00 or rented for \$10.00.

Planned Parenthood Federation of America

810 Seventh Avenue
New York, NY 10019
212-541-7800
1-800-230-7526 (for referral to local office)

Planned Parenthood Federation of America serves as a clearinghouse and library of over 20,000 items including curricula, pamphlets, books for professionals, and bibliographies. They also house several articles and an extensive reference collection regarding sexuality issues for people with disabilities. The Planned Parenthood program is available to individuals at the national and local level via the Planned Parenthood offices in each town. The organization recommends starting at the local level and then contacting the Planned Parenthood Federation of America if you need additional information. Most library services are free or have a minimal charge.

Sexuality Information and Education Council of the U.S. (SIECUS)

130 West 42nd Street, Suite 350
New York, NY 10036
212-819-9770
fax: 212-819-9776
Library hours: noon to 5:00 pm Eastern time
e-mail: siecus@siecus.org

This organization has materials including journals, over 5000 titles, 100 newsletters, 500 curriculum examples, and an extensive file of miscellaneous brochures, papers, etc. All materials deal with sexuality issues and are categorized by age groups and/or specific topic areas such as prevention of sexually transmitted diseases. Some items are specifically geared towards people with disabilities. Although the collection is non-circulating, SIECUS members can visit the library by appointment to view materials. Patrons who are not SIECUS members can receive copies of bibliography lists generated by the library. People interested in becoming SIECUS members should contact the organization for more information.



SEXUALITY AND PEOPLE WITH DISABILITIES

A Selected Bibliography

The materials listed below are available to Indiana residents from the Center for Disability Information and Referral (CeDIR), Institute for the Study of Developmental Disabilities, *The University Affiliated Program of Indiana*, 2853 E. Tenth Street, Bloomington, IN 47408-2601, 800/437-7924 (toll free in Indiana; voice/TT), 812/855-9396 (Bloomington; voice/TT).

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